THE UNITED STATES DISTRICT COURT
FOR THE MIDDLE DISTRICT OF PENNSYLVANIA

JARED MILLER, by and through his guardians, Janice Miller and Glenn Miller; ALBERT M. SPURRI, by and through his guardians, Julie Spurri and Albert J. Spurri; and DISABILITY RIGHTS NETWORK OF PENNSYLVANIA, Plaintiffs, v. DEPARTMENT OF HUMAN SERVICES OF THE COMMONWEALTH OF PENNSYLVANIA and TED DALLAS, in his official capacity as Secretary of the Department of Human Services, Defendants.	Civil Action No. _____

COMPLAINT

I. Introduction

1. Jared Miller and Albert M. Spurri, individuals with intellectual disabilities, and the Disability Rights Network of Pennsylvania (DRN) bring this lawsuit to challenge the failure of the Pennsylvania Department of Human Services (DHS) to assure that individuals eligible for the Consolidated Waiver, a Medicaid program that funds home and community-based services for individuals with intellectual disabilities, have prompt access to

residential habilitation and other services that are necessary to meet their needs and enable them to avoid institutionalization and remain in the community.

2. Plaintiffs Miller and Spurri are participants in the Consolidated Waiver who have been living at home with their families. Due to their complex and challenging needs, their families have struggled to maintain them at home with quality services funded by the Consolidated Waiver. Their families have requested residential habilitation services to secure out-of-home, community-based residential programs for them. Those efforts have proved fruitless. Indeed, Messrs. Spurri's and Miller's parents have been so frustrated by their inability to secure residential habilitation through the Consolidated Waiver that they will resort to institutional placements for their sons unless community-based programs can be promptly provided.

3. Messrs. Spurri and Miller are not unique. Numerous other Consolidated Waiver participants have been unable to promptly access residential habilitation or related services, sometimes resulting in their unnecessary institutionalization.

4. DHS's policies and practices have made it difficult for Consolidated Waiver participants with co-occurring mental health diagnoses or complex medical needs to promptly access and retain residential

habilitation and related services. These include: (a) lack of a range of crisis services geared to support individuals with dual diagnoses of intellectual disability and mental illness; (b) a rate-setting system that results in inadequate and uncertain rates to provide residential habilitation and other services to individuals with complex and challenging needs that are necessary for them to avoid institutionalization and remain in the community; (c) lack of adequate funding for start-up costs to develop new residential habilitation programs; (d) lack of consequences for providers who terminate residential habilitation services before participants can be transitioned to new programs; and (e) an inadequate number of providers and programs that are able and willing to serve participants with complex and challenging needs.

5. DRN has worked for years to address these issues with DHS, through advocacy and even litigation on behalf of Consolidated Waiver participants whose inability to timely access residential habilitation and other services resulted in or placed them at serious risk of unnecessary institutionalization. While DRN's interventions sometimes succeeded in securing some participants with the services they need, the systemic flaws that gave rise to the crises remain and, as a result, the problems continually recur.

6. DHS's failure to assure that Messrs. Miller and Spurri and other Consolidated Waiver participants have prompt access to the residential habilitation and other services necessary to avoid institutionalization to which they are entitled violates Title XIX of the Social Security Act and 42 U.S.C. § 1983.

7. Delays in access to residential habilitation and other related services have resulted in unnecessary institutionalization of some Consolidated Waiver participants and placed others at serious risk of unnecessary institutionalization in violation of Title II of the Americans with Disabilities Act and Section 504 of the Rehabilitation Act.

8. Plaintiffs seek appropriate declaratory and injunctive relief.

II. Jurisdiction and Venue

9. This Court has jurisdiction over this action pursuant to 28 U.S.C. §§ 1331, 1343(a)(3), and 1343(a)(4).

10. Plaintiffs' claims are authorized by 42 U.S.C. §§ 1396, 1983, and 12133, 29 U.S.C. § 794, and 28 U.S.C. §§ 2201 and 2202.

11. Venue is appropriate in this district pursuant to 28 U.S.C. § 1391(b) since Defendants reside in this district.

III. Parties

12. Plaintiff Jared Miller is a 37-year-old resident of Lehigh County, Pennsylvania. Mr. Miller brings this action by and through his parents and guardians, Janice Miller and Glenn Miller.

13. Plaintiff Albert M. Spurri is a 25-year-old resident of Bucks County, Pennsylvania. Mr. Spurri brings this action by and through his parents and guardians, Julie Spurri and Albert J. Spurri.

14. Plaintiff DRN is a non-profit Pennsylvania corporation. DRN and its constituents, individuals with intellectual disabilities, have been injured as a result of the Defendants' violations of federal law that are the subject of this Complaint.

a. The Commonwealth of Pennsylvania has designated DRN as the protection and advocacy system pursuant to the federal Developmental Disabilities Assistance and Bill of Rights Act (DD Act), 42 U.S.C. §§ 15041-15045.

b. Under the DD Act, DRN has the authority and duty to protect the rights of and advocate for individuals with intellectual and other developmental disabilities through, *inter alia,* the use of legal remedies. 42 U.S.C. § 15043(a)(2)(A). This authority includes the right to bring suit against the state or its agencies, and the state cannot restrict DRN's

authority to pursue legal remedies. 42 U.S.C. § 15044(b)(1); 45 C.F.R. § 1386.21(c).

c. Under the DD Act, DRN has the authority and duty to investigate allegations of neglect of individuals with developmental disabilities, including the failure to establish and implement appropriate individual support plans. 42 U.S.C. § 15043(a)(2)(B); 45 C.F.R. § 1386.19.

d. The DD Act requires that DRN's governing board must be composed of individuals who broadly represent and are knowledgeable about the needs of individuals with disabilities and that a majority of board members must be individuals with disabilities, including those with developmental disabilities as well as parents, family members, guardians, or advocates for individuals with disabilities. 42 U.S.C. § 15044(a).

e. Federal law requires DRN to annually establish goals and priorities based on public input. 45 C.F.R. §§ 1386.22(c)-(d).

f. The DD Act requires that DRN have a grievance procedure available to assure individuals with developmental disabilities have full access to DRN's services. 42 U.S.C. § 15043(a)(2)(E).

g. DRN provides information and referral services, individual representation, education, and other services to individuals with intellectual disabilities on an array of issues – including, *inter alia,* abuse and neglect;

access to community-based services; access to health care; unnecessary institutionalization; and discrimination in housing, employment, government services, and public accommodations.

h. As described below, DRN has spent time, money, and resources assisting Consolidated Waiver participants who, due to their inability to promptly access residential habilitation and other related services, were unnecessarily institutionalized or at risk of unnecessary institutionalization. These expenditures of time, money, and resources diverted DRN staff from other activities that they could have undertaken for their constituents.

i. DRN's constituents include Plaintiffs Spurri and Miller and other Consolidated Waiver participants who have been harmed by their inability to promptly access residential habilitation services due to Defendants' policies, practices, and procedures.

15. Defendant Department of Human Services of the Commonwealth of Pennsylvania (DHS) is the single state agency that has responsibility to implement Pennsylvania's Medical Assistance Program, including home and community-based waiver services provided to individuals with disabilities. 42 U.S.C. § 1396a(a)(5); 55 Pa. Code § 101.1(e).

16. Defendant Ted Dallas is the Secretary of DHS. Mr. Dallas is responsible to assure that Pennsylvania's Medical Assistance program is operated in compliance with federal law. Mr. Dallas is sued only in his official capacity for actions and omissions under color of state law.

IV. Factual Background

A. Pennsylvania's Medicaid Program

17. Title XIX of the Social Security Act (Title XIX), 42 U.S.C. § 1396 *et seq.*, establishes the federal Medical Assistance (Medicaid) program.

18. Medicaid is a cost-sharing arrangement under which the federal government reimburses more than 50 percent of the expenditures incurred by participating states for Medicaid services to individuals whose income and resources are insufficient to cover the costs of their medical care.

19. The purpose of Medicaid is to provide services to eligible individuals, including services to help such individuals "attain or retain capability for independence or self-care ...." 42 U.S.C. § 1396-1.

20. States are not required to participate in the Medicaid program, but if they choose to do so they must adopt a "state plan" that delineates the standards for determining eligibility and the services available.

21. Pennsylvania has chosen to participate in the Medicaid program and has adopted a State Plan.

22. Title XIX delineates the types of medical services that can be funded under a state's Medicaid plan, some of which are mandatory and some of which are optional. *See* 42 U.S.C. § 1396d.

23. In addition to the mandatory and optional Medicaid services listed in Title XIX, Title XIX also permits a state to obtain "waivers" to provide home and community-based services (HCBS waivers) from the federal Centers for Medicare and Medicaid Services (CMS). 42 U.S.C. § 1396n(c).

24. The purpose of HCBS waivers is to encourage states to provide services to enable individuals with disabilities to avoid institutionalization. 42 C.F.R. § 441.300.

25. HCBS waivers allow states to include in their state plans as "Medical Assistance" home and community-based services, including services that otherwise could not be funded by Medicaid (such as residential habilitation and respite), for individuals who, without such care, would require institutionalization in intermediate care facilities for individuals with intellectual disabilities (ICFs/IID), nursing facilities, or hospitals. 42 U.S.C. § 1396n(c)(4)(B); 42 C.F.R. § 440.180.

26. HCBS waivers allow states to waive certain requirements that apply to mandatory and optional Medicaid services. 42 U.S.C. § 1396n(c)(3).

27. States can limit the number of persons who can participate in a HCBS waiver and limit eligibility based on age, disability, or other criteria.

B. Consolidated Waiver

28. Pennsylvania has received approval from CMS to operate multiple HCBS waivers, including the "Consolidated Waiver."

29. DHS, the single state agency designated by Pennsylvania to administer its Medical Assistance program, has delegated responsibility to administer the Consolidated Waiver to its Office of Developmental Programs (ODP).

30. The Consolidated Waiver, established in 1986, provides services to Pennsylvanians with intellectual disabilities age 3 and older who need the level of care provided by an ICF/IID.

31. The Consolidated Waiver is the largest HCBS waiver in the Commonwealth, both in terms of the number of individuals served and expenditures.

32. The Consolidated Waiver is the primary funding source for community-based intellectual disability services in Pennsylvania.

33. The Consolidated Waiver limits the number of individuals who can receive services. Currently, the limit is approximately 18,000 persons.

34. The Consolidated Waiver offers a broad range of community-based services, including:

a. Residential habilitation – This provides 24-hour services to participants who live in provider-owned, rented/leased, or operated residential settings to assist them to acquire, retain, and improve their self-help, socialization, and adaptive skills necessary to live successfully in their homes and the community. This service can be provided in homes that serve as few as one person. If needed, enhanced staffing may be provided, allowing for nursing services or 1:1 or 2:1 staffing for a participant. Residential habilitation programs must be integrated and dispersed in the community.

b. Home and community-based habilitation – This is a non-residential service that helps participants to acquire, maintain, and improve their self-help, domestic, socialization, and adaptive skills to reside successfully in their own homes and communities.

c. Behavioral support – This provides services to conduct a functional assessment and develop strategies based on the assessment to

meet the behavioral needs of the participant, including training the participant, parents, caregivers, and staff.

d. Nursing – Registered or licensed nursing staff will be provided in family homes or residential habilitation settings if needed.

e. Respite – Respite is provided to participants living in private homes to provide short-term relief for caregivers. Respite can also be offered in emergency circumstances to participants living in residential habilitation programs. Respite is capped at 30 days of 24-hour respite and 120 hours of temporary respite per year, although ODP can authorize a greater amount as an exception.

f. Supports coordination – This is a case management service that assists participants to locate, coordinate, and monitor services and supports.

35. DHS contracts with local Administrative Entities (AEs) to perform operational and administrative functions to implement the Consolidated Waiver. In most instances, the AEs are the County Mental Health and Intellectual Disability (MH/ID) Programs.

36. Once an individual is approved to participate in the Consolidated Waiver, he or she and his or her Support Team (including involved family or guardian and supports coordinator) work to develop an Individual

Support Plan (ISP) to identify the supports and services the individual needs to live in the community.

37. Supports coordinators are responsible to facilitate the development, management, and review of participants' ISPs.

38. The ISP, which must be approved by the AE and ODP, is the document that authorizes the home and community-based services that the individual will receive under the Consolidated Waiver.

39. The services and supports identified in an ISP should be based on the individual's current clinical and medical needs assessed pursuant to the ODP-approved needs assessment instrument.

40. When an individual's service needs change (*e.g.*, he or she needs a different type of service, more of a service, or less of a service), his or her ISP should be amended to reflect the change. However, an amendment to the ISP will be made only after a willing service provider is identified. The AE and ODP must then authorize any new or different services in a revised ISP.

41. Whether or not changes are necessary, the ISP must be re-evaluated at least once a year, and the AE and ODP must reauthorize the services.

42. Defendants are responsible to assure that Consolidated Waiver participants have timely access to the Waiver services that they want and need, including residential habilitation. This responsibility includes establishing a system, including an adequate network of providers, which enables Consolidated Waiver participants to timely access such services.

43. If the system worked as it should, a Consolidated Waiver participant who wants and needs residential habilitation or other services would inform his supports coordinator who would include that service in his ISP. The participant would then have access to a choice of providers willing to offer them those services, and they would choose a provider.

44. Instead, the ISPs of Consolidated Waiver participants who request and need a new service – such as residential habilitation – will not be amended until willing providers are located.

45. Even when the ISP indicates that a service is authorized for the Consolidated Waiver participant, it does not reflect whether that service is actually being provided.

46. For individuals who are enrolled in the Consolidated Waiver, there is no monetary cap on services. Participants are entitled to receive any services they need that are available under the Waiver and that are necessary for their health and welfare, regardless of cost.

47. Consolidated Waiver participants who are institutionalized in medical or psychiatric hospitals or in nursing facilities will be terminated from the Waiver.

48. Although DHS reserves slots in the Consolidated Waiver to serve individuals who are institutionalized in ICFs/IID and to serve former Consolidated Waiver participants who have been in medical or psychiatric hospitals or nursing facilities for less than six months, former Consolidated Waiver participants who are hospitalized or placed in nursing facilities for more than six months will be placed on a waiting list for the Waiver.

49. There are thousands of Pennsylvanians on the "emergency" waiting list for Consolidated Waiver services so that former Consolidated Waiver participants who are subject to long-term institutionalization may have to wait years to be re-enrolled.

C. The Inability of Plaintiffs Spurri and Miller and Other Consolidated Waiver Participants to Access or Maintain Residential Habilitation Services

1. Jared Miller

50. Plaintiff Jared Miller is a 37-year-old man with Cornelia de Lange Syndrome, a genetic disorder that for him results in intellectual disability, physical disabilities, medical issues, and behavioral health issues

(including oppositional defiant disorder and obsessive compulsive disorder).

51. Mr. Miller's impairments substantially limit his ability to think, learn, care for himself, and interact with others.

52. Mr. Miller is eligible for and participates in the Consolidated Waiver.

53. Mr. Miller has always lived in his family home with his parents.

54. Mr. Miller's ISP authorizes him to receive 24 hours daily of in-home nursing services and 24 hours daily of community habilitation services so that he is to have two staff people with him around-the-clock. These services are provided by multiple private providers as well as Mr. Miller's father, who is paid to provide 40 hours weekly of habilitation services.

55. Mr. Miller requires a gastrostomy tube (G-Tube) to allow gas and liquids to be evacuated from his stomach. Mr. Miller requires a gastrojejunostomy tube (G-J Tube) to be fed and receive nutrition. Both devices are inserted into sites on his abdomen that require constant monitoring to prevent infection and pain. Staff must also monitor Mr. Miller constantly to prevent him from pulling out the tubes.

56. Mr. Miller takes many medications and receives various medical treatments daily. He receives medications to control his pain, symptoms of his obsessive compulsive disorder, diabetes, and cholesterol. He receives daily nebulizer treatments for allergies and antibiotic eye drops since he had retinal attachment surgeries in early 2015.

57. Staff must monitor Mr. Miller for any indications of irregular blood chemistries. If any abnormalities are noted, staff draw his blood and his physicians evaluate it to determine if adjustments are needed to his feedings, medications, or nutritional supplements.

58. Mr. Miller requires multiple medical appointments with specialists at Hershey Medical Center, more than 1.5 hours from his home, as well as local medical and dental appointments. Mr. Miller's father schedules and together with support staff attends his appointments.

59. Mr. Miller has episodes of pain that can cause him to engage in self-injurious behaviors (inflicting injuries to his head, eyes, and hands) and throw himself out of his bed or wheelchair.

60. These behaviors resulted in retinal detachments that required him to undergo surgery. Whiplash-like movements of his head exacerbated his detached retinas, and he has had multiple repair surgeries.

61. Mr. Miller requires two people to attend to him to prevent significant injuries.

62. Mr. Miller sometimes uses flexible elbow immobilizers and hand mittens to physically restrain his hands at night to prevent further injuries during pain episodes.

63. Mr. Miller needs total assistance to complete his activities of daily living, including bathing, brushing his teeth, dressing, eating, and changing his adult diapers.

64. Mr. Miller needs to have someone hold his hand and physically assist him when he walks. While he is able with such assistance to walk short distances, he relies on a wheelchair to travel longer distances.

65. Mr. Miller and his family must rely on staff funded through the Consolidated Waiver to provide him with the care and supports he needs, including assistance with his daily living activities, administration of medication, monitoring his G-Tube and G-J Tube.

66. Mr. Miller and his family also must rely on staff funded through the Consolidated Waiver to assist Mr. Miller to participate in the community activities that he enjoys, such as going to stores, amusement parks, playgrounds, movies, and malls.

67. Although Mr. Miller is authorized to receive 24 hours daily of nursing and habilitation services, there are hours each week when staff are unavailable to provide the authorized amount of services. When Mr. Miller's providers cannot send staff, his parents must fill in and provide both nursing and habilitation services.

68. Mr. Miller's mother is 64 years old. She is employed full-time as a teacher, working one hour away from home and will not retire until she is 70.

69. Mr. Miller's father is 69 years old. He not only provides 40 hours of his habilitation, but also makes sure that all of his medications and supplies are ordered, schedules staff, takes him to all of his medical and dental appointments, coordinates all community outings, and covers uncovered staff hours.

70. As Mr. Miller's parents grow older, they are encountering their own physical limitations. These limits, as well as their inability to assure stable staffing for Mr. Miller at home, led them about 10 years ago to begin to explore the possibility of residential habilitation for Mr. Miller.

71. Due to the risk that Mr. Miller may blind himself if he continues to inflict retinal damage, his parents intensified their search for a residential habilitation program between 2010 and 2011. At that time, Mr. Miller's

supports coordinator contacted many residential habilitation providers, but none were willing to serve him.

72. In 2012, a provider, Horizon House, indicated it was willing to provide residential habilitation to Mr. Miller with one other housemate. Unfortunately, Horizon House stopped development of that program, apparently due to a funding dispute with ODP.

73. Growing increasingly desperate to find a residential program for Mr. Miller, his parents in February 2014 instructed his supports coordinator to try to identify an ICF/IID willing to serve Mr. Miller, even though he would lose his eligibility for the Consolidated Waiver if he accepted ICF/IID services.

74. ICFs/IID are often large, congregate programs that are less integrated, impose more restrictions, and provide less access to community activities than residential habilitation programs funded by the Consolidated Waiver.

75. In December 2014, Mr. Miller was referred to a private ICF/IID, but in January 2015 his parents learned that he was not accepted.

76. On March 10, 2015, Mr. Miller's parents informed the AE and his supports coordinator that they could no longer wait and needed a residential program for Mr. Miller immediately. Mr. Miller's supports

coordinator began a statewide search for residential habilitation providers through the Consolidated Waiver and ICFs/IID.

77. In or around April 2015, a provider, Supportive Concepts for Families, Inc. (SCFFI), expressed an interest in serving Mr. Miller, but ultimately decided it was unable to provide him services. Mr. Miller's parents were devastated and disheartened by this decision.

78. Although neither the provider nor DHS provided Mr. Miller's parents with formal notice of the denial or appeal rights, they filed a request for a fair hearing on May 16, 2015 with DHS's Bureau of Hearings and Appeals. In the appeal, Mr. Miller's mother requested that she and her husband be permitted to visit two of the state-operated ICFs/IID as potential placements for Mr. Miller, even though DHS will not admit anyone to those facilities absent a court-ordered commitment.

79. In the summer of 2015, while waiting for the administrative hearing, Mr. Miller's parents emailed DHS Secretary Dallas, spoke with the Northeast Program Manager of ODP's Bureau of Supports for People with Intellectual Disabilities, and wrote to the AE to reiterate their requests for a residential program for Mr. Miller.

80. On October 23, 2015, Sharon Johnson, the Executive Secretary to the Deputy Secretary for DHS's Office of Long Term Living,

contacted Mr. Miller's parents to follow up on their earlier email to Secretary Dallas. Ms. Johnson inquired about the services that Mr. Miller received from DHS and if he still needed assistance. Mr. Miller's mother responded by email the same day to explain Mr. Miller's urgent need for residential services and his inability to timely access such services and asked for help. After sending that email, Mr. Miller's parents heard nothing further from DHS.

81. On October 22, 2015, a private ICF/IID provider met with Mr. Miller and his parents to evaluate whether to admit him to one of their ICFs/IID. In mid-December 2015, the provider declined to serve Mr. Miller.

82. On November 30, 2015, DHS's Bureau of Hearings and Appeals heard evidence on the appeal filed by Mr. Miller. No DHS officials or staff attended. In response to an inquiry as to whether Mr. Miller would have a placement within the next twelve months, the AE staff testified that they could not estimate how long it would take to find him an appropriate placement. When asked what would happen if Mr. Miller's parents died suddenly, the AE's representative acknowledged that it would need to find a residential provider for Mr. Miller, but could not currently offer any viable options.

83. In December 2015, the Bureau of Hearings and Appeals dismissed Mr. Miller's appeal for lack of jurisdiction.

84. After many years of searching and contacting local and state officials for help, no residential habilitation provider has been identified who is willing to serve Mr. Miller. Mr. Miller continues to live in his parents' home while they struggle to meet his significant needs.

2. Albert M. Spurri

85. Albert M. Spurri is a 25-year-old man with an intellectual disability that substantially limits his ability to think, learn, care for himself, and interact with others.

86. Mr. Spurri is eligible for and participates in the Consolidated Waiver.

87. Mr. Spurri currently lives at home with his parents. Mr. Spurri has a close relationship with his family.

88. Mr. Spurri enjoys living in the community and participating in community life. He goes to the gym, bowling, and horseback riding. He enjoys helping his father with house maintenance and mowing the lawn. He likes to spend time with his dog. He particularly enjoys attending church.

89. While Mr. Spurri has good receptive communication skills (including understanding and following instructions), he has limited expressive communication skills. He can say a few words, but otherwise uses a communication application on his iPad and iPod, or points to pictures or objects to communicate his needs or desires.

90. Mr. Spurri experiences migraine headaches, which can cause him significant pain.

91. Mr. Spurri typically wants more food than he needs to maintain a healthy weight, and currently is overweight.

92. As a result of his limited expressive communication skills, the pain from his migraines, and his desire for more food, Mr. Spurri can become frustrated and his frustration can lead to physical aggression.

93. Due to his size, weight, and physically aggressive behavior, Mr. Spurri's parents have found it increasingly difficult to maintain him safely in their home.

94. Occasionally, in fear for their safety, Mr. Spurri's parents have locked themselves behind a door until their son calms down.

95. Currently, the primary services that Mr. Spurri is authorized to receive through the Consolidated Waiver are a prevocational program five

days a week; home and community habilitation for about 16 hours per week; behavioral support; respite; and supports coordination.

96. In September 2014, Mr. Spurri's mother contacted his supports coordinator to request residential services for him.

97. On information and belief, Mr. Spurri's supports coordinator referred Mr. Spurri to at least 20 residential habilitation programs between October 2014 and March 2015. Only one of those 20 programs agreed to serve Mr. Spurri, but it conditioned its agreement on the use of physical restraints when Mr. Spurri becomes upset.

98. Mr. Spurri has a behavior plan in place at his prevocational program that has proven successful. Using that plan, Mr. Spurri has 1:1 male staff and when he gets upset his staff take him outside and leave him alone in the fenced yard while monitoring him. When he is outside, he is able to calm himself. Since this plan has been developed, Mr. Spurri has made a great deal of progress in controlling his physical aggression, and he has not had any serious incidents since September 2014 at his prevocational program.

99. Mr. Spurri's behavior specialist concluded that using any type of restraint on him would be extremely dangerous for him and staff as he

becomes much more aggressive when attempts are made to physically manage him.

100. Given the opinion of Mr. Spurri's behavior specialist that restraints should not be used and the successful, non-restrictive behavior plan implemented at the prevocational program, Mr. Spurri's parents declined to allow him to be placed in a residential program that was conditioned on use of physical restraints.

101. In the summer of 2015, Mr. Spurri's supports coordinator referred him to four other residential providers, but they either had no residential vacancies that would meet his requirements or they were unwilling to serve him due to concerns about his aggressive behaviors.

102. On information and belief, the residential habilitation providers who rejected Mr. Spurri due to his behavioral issues were unwilling to utilize his current behavior plan, which is working well at his prevocational program, because it was deemed "restrictive."

103. Mr. Spurri has never been offered a one-person residential habilitation program.

104. It has been over 15 months since Mr. Spurri's parents began their quest for a residential habilitation program to serve their son, but their efforts have yielded no results and he remains living in their home.

105. Mr. Spurri's parents are under increasing stress as it becomes ever more difficult to maintain him in their home.

106. Mr. Spurri's parents are willing to place him in an ICF/IID, even though he would lose his eligibility for the Consolidated Waiver if he accepted those services and even those ICFs/IID are often more restrictive and less integrated than residential habilitation programs funded by the Consolidated Waiver.

3. Other Exemplars

107. In addition to Plaintiffs Miller and Spurri, DRN is aware and has sometimes intervened on behalf of other Consolidated Waiver participants who, because they were unable to promptly secure or maintain residential habilitation and other related services, experienced institutionalization or were placed at serious risk of institutionalization.

108. Although the Consolidated Waiver participants who experience these problems have disabilities that are challenging or complex so that they are difficult to serve, the availability of timely and appropriate interventions would enable them to remain in the community.

109. DHS's position is that all Consolidated Waiver participants are able to be served in the community.

a. James Marston

110. James Marston, a resident of Bucks County, is a Consolidated Waiver participant.

111. In addition to an intellectual disability, Mr. Marston has a seizure disorder. These disabilities substantially limit his major life activities, including thinking, learning, and caring for himself.

112. Mr. Marston had been receiving residential habilitation and other services through the Consolidated Waiver when in June 2013 he suffered a brain injury that resulted in his loss of skills and impaired his ability to communicate.

113. Following his brain injury, Mr. Marston's residential habilitation provider notified him that it would terminate his services effective April 30, 2014.

114. After receiving this termination notice, Mr. Marston's supports coordinator and his family attempted to locate another residential habilitation provider for him without success.

115. Mr. Marston's AE indicated that it would file a petition to involuntarily commit Mr. Marston to a state-operated ICF/IID because DHS was unable to locate a residential habilitation provider for him.

116. DRN intervened on behalf of Mr. Marston, filing a federal complaint, *James Marston v. Dep't of Human Services,* No. 14-cv-2400 (E.D. Pa.), and a motion for a temporary restraining order to prevent Mr. Marston's unnecessary institutionalization.

117. As a result of DRN's intervention, DHS located another provider to serve Mr. Marston and convinced his then-current provider to continue to serve him until the new program was operational.

b. J.H. 1

118. J.H. 1, a resident of Philadelphia, is a Consolidated Waiver participant.

119. In addition to an intellectual disability, J.H. 1 has schizophrenia and other mental health diagnoses. Her disabilities substantially limit her major life activities, including thinking, learning, caring for herself, and interacting with others.

120. J.H. 1 had been receiving residential habilitation and other services through the Consolidated Waiver when in May 2014 she was hospitalized for psychiatric issues.

121. When J.H. 1 was hospitalized, her residential habilitation provider issued a notice terminating her services effective June 15, 2014.

122. J.H. 1's supports coordinator attempted to locate another residential habilitation provider for her. One provider, InVision Human Services (InVision), was willing to provide J.H. 1 with residential habilitation services, but could not establish the program until January 2015.

123. J.H. 1 was ready to be discharged from the hospital on or about July 23, 2014, but she remained hospitalized because DHS could not identify either a residential habilitation provider available and willing to serve her at that time or a respite care provider willing to serve her pending development of the InVision program.

124. On July 28, 2014, the hospital referred J.H. 1 to a homeless shelter for her "discharge plan" in the absence of any services under the Consolidated Waiver.

125. DRN intervened on behalf of J.H. 1 to prevent her continued unnecessary hospitalization, precipitous discharge to a homeless shelter, or unnecessary commitment to a state institution. DRN spent many hours in this endeavor, contacting county and DHS staff; attending meetings to advocate for J.H. 1 to receive appropriate community services through the Consolidated Waiver; urging hospital staff not to discharge her to a homeless shelter or non-Waiver services; and drafting a federal complaint

and motion for a temporary restraining order to prevent J.H. 1's homelessness or unnecessary institutionalization.

126. After DRN advised DHS that it intended to file a lawsuit and seek emergency relief for J.H. 1, DHS was able to identify a provider willing to offer residential habilitation services to her.

127. Since the residential habilitation program for J.H. 1 would not be ready until August 27, 2014 and DHS could not identify respite services she could use in the interim, J.H. 1 was hospitalized unnecessarily in a subacute psychiatric unit until her residential habilitation program was ready.

c. A.M.

128. A.M., a resident of Huntingdon County, has an intellectual disability, mood disorder NOS, and borderline personality disorder. Her disabilities substantially limit her major life activities, including thinking, learning, caring for herself, and interacting with others.

129. A.M. was enrolled in the Consolidated Waiver and began receiving residential habilitation services in a group home in Huntingdon County in December 2011.

130. In January 2013, A.M. became self-injurious. Her residential habilitation provider contacted crisis services, which transported her to a private hospital for mental health treatment.

131. When she was hospitalized, A.M.'s residential habilitation provider notified her that it was terminating her services.

132. A.M.'s supports coordinator was unable to identify any other providers interested in serving her due to her behavioral issues, even though a behavior specialist had developed a behavior support plan and a team (consisting of both intellectual disability and mental health professionals) had been formed to help A.M.

133. With nowhere to go, A.M. was transferred from the private hospital to Danville State Hospital in February 2013.

134. A.M.'s mental health and behavioral issues improved, and she was ready for discharge from Danville State Hospital beginning in early 2014.

135. In or around late 2013, InVision agreed to develop a residential habilitation program for A.M. in southeastern Pennsylvania, close to where her mother lives, but stated it would take seven months before the program would be ready.

136. By March 2015 – a year after A.M. was ready for discharge – InVision had not developed a program for her and she remained at Danville State Hospital. At that time, InVision stated that it had put its program development for A.M. on hold because of lack of funding from ODP. Although A.M. wanted to wait for InVision, the state hospital could not continue to justify her institutionalization since she had been doing so well for so long.

137. In or around October 2015, DHS identified another provider willing to develop a one-person residential habilitation program for A.M. in Reading.

138. A.M. is currently scheduled for discharge in January 2016 – nearly two years beyond the time she was ready to leave.

139. A DRN lay advocate has advocated for A.M. since November 2012. Prior to her institutionalization, the lay advocate attended the Positive Practices Resource Team meetings and worked with her support team in efforts to enable her to remain in the community. Since A.M.'s admission to Danville State Hospital, the lay advocate has attended A.M.'s Community Service Plan meetings, met with her and her mother, and advocated for an appropriate discharge plan.

d. J.S.

140. J.S. is a resident of Clarion County who has an intellectual disability, schizophrenia, impulse control disorder, and atypical psychosis. His disabilities substantially limit his major life activities, including thinking, learning, caring for himself, and interacting with others.

141. J.S. was enrolled in the Consolidated Waiver and began receiving residential habilitation services from SCFFI, funded by that Waiver, in March 2013.

142. SCFFI notified J.S. on November 27, 2013 that it was no longer willing to serve him. SCFFI stated that it was not able to support J.S. safely or address the intensity of his clinical needs effectively.

143. Although J.S.'s supports coordinator began looking for a new residential habilitation provider when SCFFI issued the termination notice, she was unable to find one.

144. SCFFI continued to provide services to J.S. until December 18, 2013 when he was admitted to the Horsham Clinic due to psychiatric issues.

145. SCFFI refused to take J.S. back into the residential program after he was hospitalized, and he remained at the Horsham Clinic.

146. On July 2, 2014, ODP notified DRN that J.S. was at risk of an involuntary commitment to a state-operated ICF/IID due to the lack of any willing residential habilitation provider to serve him.

147. After receiving that notice, a DRN lay advocate visited J.S. at the Horsham Clinic and communicated with his supports coordinator.

148. DRN's attorneys also began work on potential litigation to intervene to prevent J.S.'s unnecessary institutionalization.

149. Prior to initiating litigation, DRN learned that two residential habilitation providers advised ODP that they would be willing to serve J.S., but that it would take at least six months to develop an appropriate program for him. The providers indicated that the unavailability of adequate start-up funds made in financially infeasible to develop a program for J.S.

150. Two other providers also told ODP that they were willing to provide residential habilitation services to J.S., but one said it would take a year to develop a program and the other indicated that it could not have a program ready until at least November 2014.

151. Although J.S. was appropriate for discharge from the Horsham Clinic in or around July 2014, he remained institutionalized unnecessarily until November 2014 when he was able to move to a new residential habilitation program.

e. T.B.

152. T.B., a resident of Philadelphia, has an intellectual disability, attention deficit hyperactive disorder, disruptive behavior disorder, and mixed receptive-expressive language disorder. His disabilities substantially limit his major life activities, including thinking, learning, caring for himself, and interacting with others.

153. T.B. was enrolled in the Consolidated Waiver and received residential habilitation services funded by that Waiver.

154. In April 2014, T.B. was admitted to a private psychiatric hospital.

155. T.B.'s residential habilitation provider terminated him after his admission to the psychiatric hospital.

156. In May 2014, when T.B. was ready for discharge from the psychiatric hospital, there were no other residential habilitation providers able and willing to serve him and he went home to live with his parents.

157. Although T.B. received some in-home supports funded by the Consolidated Waiver, living with his family was not an appropriate placement for him. T.B. sometimes refused to cooperate with staff, became assaultive toward his mother and staff, destroyed property, and attempted to injury himself.

158. In less than a month, T.B. was involuntarily committed to a psychiatric hospital in June 2014. Although T.B. was stabilized and ready for discharge within two weeks, his parents refused to allow him to return home due to concerns about T.B.'s and their own health and safety.

159. A DRN lay advocate intervened, contacting T.B.'s AE to try to identify an alternative placement for T.B. Although a residential habilitation provider willing to serve T.B. had been identified, it would not be able to have the program ready until July 2014. As a result, the AE indicated that T.B. would be homeless when the hospital discharged him.

160. The DRN lay advocate then contacted ODP in an effort to prevent T.B.'s imminent homelessness and continued to work with T.B.'s supports coordinator to identify alternatives.

161. DRN attorneys also began to prepare litigation to prevent T.B.'s homelessness and to assure that he had access to the services to which he was entitled under the Consolidated Waiver.

162. By mid-June 2014, T.B. was ready for discharge from the psychiatric hospital and no services, even respite services, had been identified that would be able to serve him for the short time period until his residential habilitation placement was ready.

163. Ultimately, ODP transferred T.B. to a mental health crisis residential program in Delaware County because his Medicaid behavioral health insurer agreed to pay for it and because there was no Consolidated Waiver providers available and willing to even provide respite care to him for a short time. T.B. remained in the crisis program for several days until he was transferred to his residential habilitation program.

f. J.H. 2

164. J.H. 2 is a 26-year-old resident of Lackawanna County who has diagnoses of an intellectual disability, fetal alcohol spectrum disorder, borderline personality disorder, and mood disorder. Her disabilities substantially limit her major life activities, including thinking, learning, caring for herself, and interacting with others.

165. J.H. 2 was enrolled in the Consolidated Waiver in September 2008, and began receiving habilitation services in her home.

166. In November 2008, J.H. 2 moved to a residential habilitation program funded by the Consolidated Waiver. While living there, she became pregnant and gave birth to a son in September 2010.

167. J.H. 2 moved with her son to the private home of the supervisor of her residential habilitation program, who received Consolidated Waiver funding to provide “shared living” services to J.H. 2 The shared living

provider became the foster mother to J.H. 2's son, and subsequently initiated legal proceedings to gain full custody. This destroyed the relationship between J.H. 2 and the shared living provider.

168. In October 2010, J.H. 2 was admitted to a private hospital due to mental health issues, and remained there until May 2011.

169. Upon her discharge from the psychiatric hospital in May 2011, J.H. 2 moved to another residential habilitation program, but she left in December 2011 due to assaultive behaviors.

170. J.H. 2 then moved to her own apartment and received home and community-based habilitation services funded by the Consolidated Waiver. In May 2014, she was evicted from her apartment for fighting with her neighbors.

171. J.H. 2 moved to another apartment and continued to receive habilitation services funded by the Consolidated Waiver. However, her habilitation services provider terminated her in July 2014 when she reportedly injured a staff person and another provider had to be located.

172. J.H. 2 subsequently moved in with her sister and refused all services and supports available under the Consolidated Waiver. J.H. 2's mother and sister became the representative payee for her Social Security benefits and allegedly used the funds for their own needs. During the short

period that J.H. 2 lived with her sister, multiple 911 calls were made and she had multiple crisis evaluations in the emergency room due to outbursts.

173. In November 2014, J.H. 2 moved into another residential habilitation program. Between November 2014 and early February 2015, staff at the program contacted the local police department eight times when J.H. 2 had outbursts resulting in property destruction, aggression towards others, and self-injurious behaviors. These repeated police calls led to issuance of a notice to the provider on February 12, 2015 that the home would be designated as a nuisance property.

174. On February 16, 2015, J.H. 2 was involuntarily committed to a private hospital for psychiatric treatment after she attempted suicide.

175. J.H. 2 was ready to be discharged from the private hospital on March 23, 2015, but her residential habilitation provider would not allow her to return to the home.

176. When it appeared that the private hospital might discharge J.H. 2 to her sister's care, the County MH/ID Program filed a petition for appointment of an emergency guardian to prevent that outcome due to concerns that J.H. 2 had been subject to financial exploitation by her sister.

177. On March 26, 2015, the court appointed an emergency guardian of the person for J.H. 2 and the residential habilitation provider issued a formal termination notice to the emergency guardian.

178. ODP requested that a DRN lay advocate work on J.H. 2's behalf to help secure appropriate home and community-based services under the Consolidated Waiver.

179. J.H. 2's support team, including the DRN lay advocate, met frequently to try to identify a new residential habilitation program for her, but they could not identify any interested providers due to her behavioral issues and she remained in the private hospital.

180. On April 7, 2015, the private hospital filed a petition to involuntarily commit J.H. 2 to a state ICF/IID.

181. Prior to the scheduled commitment hearing on April 16, 2015, J.H. 2's team identified a residential habilitation provider who might be willing to serve her. J.H. 2 was scheduled to meet with that provider on April 27, 2015. The court agreed to stay any ruling on the commitment petition pending the outcome of the provider's meeting with J.H. 2

182. After the provider met with J.H. 2, it advised her team that it was not willing to serve her.

183. At the continued hearing on April 30, 2015, the court involuntarily committed J.H. 2 to a state ICF/IID, and she was transferred there in June 2015.

184. Despite her participation in the Consolidated Waiver, J.H. 2 spent three months unnecessarily institutionalized in a psychiatric hospital and has been unnecessarily institutionalized in a state ICF/IID for the past seven months with no end in sight due to the inability to identify willing residential habilitation providers.

g. K.J.

185. K.J., a resident of Allegheny County, has an intellectual disability and mood disorder NOS. Her disabilities substantially limit her major life activities, including thinking, learning, caring for herself, and interacting with others.

186. At age 10, the Allegheny County Office of Children, Youth and Families removed K.J. from her mother's care due to physical and emotional abuse.

187. K.J. was enrolled in the Consolidated Waiver in July 2008, receiving residential habilitation services. Between July 2008 and October 1, 2014, K.J. moved among several different residential habilitation

programs, all of which were operated by the same provider. During this timeframe, K.J. was on probation for theft and false allegations.

188. On October 1, 2014, K.J. moved to another residential habilitation program operated by a different provider.

189. Within days of this move, K.J. reported to her supports coordinator that she was very unhappy in her new home and threatened suicide. Her supports coordinator contacted crisis services and K.J.'s probation officer. K.J. was involuntarily committed to Western Psychiatric Institute and Clinic (WPIC) for mental health treatment on October 9, 2014.

190. Within a short time, K.J. was ready for discharge from WPIC, but her provider refused to take her back to her residential habilitation program.

191. Since K.J. was not allowed to be homeless while on probation, her probation officer took her from WPIC to the Washington County jail on October 17, 2014.

192. Upon information and belief, K.J. was released from the Washington County jail to a diversion/stabilization program for temporary treatment on December 4, 2014.

193. On December 19, 2014, K.J. was admitted to Mercy Crisis Response Center, a temporary mental health crisis shelter, in Allegheny

County because she had nowhere else to go, including no residential habilitation program willing to accept her.

194. Since she could not stay at the mental health crisis shelter for more than 30 days and she had nowhere else to go, K.J. was discharged to her mother's home on January 20, 2015.

195. On January 23, 2015, K.J. voluntarily admitted herself to a private hospital's behavioral health unit.

196. K.J. was not able to return to her mother's home after she stabilized. So, on January 28, 2015, her probation officer returned her to jail.

197. On April 17, 2015, K.J. was released from jail. Since she still had no residential habilitation program or other residential options, K.J. returned to Mercy Crisis Response Center.

198. Upon information and belief, the Allegheny County Department of Human Services filed a petition to involuntarily commit K.J. to a state-operated ICF/IID on April 21, 2015. Before a hearing on that petition could be held, Mercy Crisis Response Center initiated an involuntary psychiatric commitment of K.J. for suicidal ideation on May 6, 2015. K.J. subsequently agreed to voluntarily admit herself for psychiatric treatment.

199. On May 20, 2015, the Allegheny County Court of Common Pleas held a hearing on the petition to involuntarily commit K.J. to a state-operated ICF/IID. The Court granted the petition, and ordered K.J. to be committed to Polk Center. K.J. was transferred to Polk Center on June 2, 2015, where she remains.

200. Due to DHS's failure to secure appropriate residential habilitation services for K.J., she bounced between jail, mental health treatment and crisis centers, psychiatric hospitals, and her mother's home for close to nine months and has been unnecessarily institutionalized in a state ICF/IID for more than seven months.

h. J.C.

201. J.C., a resident of Luzerne County, has an intellectual disability and was a Consolidated Waiver participant. Her disabilities substantially limit her major life activities, including thinking, learning, caring for herself, and interacting with others.

202. J.C. was receiving residential habilitation and other waiver services in the community until approximately August 2014, when she started exhibiting aggressive behaviors.

203. J.C. was hospitalized for a medical evaluation, and then admitted to First Hospital for psychiatric hospitalization on or around August 6, 2014.

204. On August 22, 2014, J.C.'s residential habilitation provider indicated that it no longer would provide services to her.

205. When J.C. became ready for discharge, J.C. remained hospitalized at First Hospital while her supports coordinator attempted to locate a community provider for her by contacting providers on the vacancy list. No provider was located to serve J.C.

206. The county and J.C.'s team determined that she needed ongoing mental health services to help her transition from inpatient care, but because of the lack of resources for individuals with intellectual disabilities needing mental health care, a community provider could not be located and J.C. was being considered by her team for admission to a state psychiatric hospital or a state center.

207. On information and belief, one of the state psychiatric hospitals, Clarks Summit, evaluated J.C. and determined that she did not need psychiatric hospitalization.

208. DRN wrote to DHS on September 19, 2014 about J.C.'s potential unwarranted commitment and requested intervention to prevent unnecessary institutionalization.

209. On or about October 21, 2014, a petition to commit J.C. was filed, and a hearing was held three days later.

210. In early December 2014, J.C. was transferred to Hamburg State Center, one of the state-operated ICFs/IID, because DHS could not locate a provider to provide services in the community.

211. On or around December 28, 2014, J.C. died at Hamburg State Center. She had just turned 28 years old.

i. D.L.

212. D.L., a resident of Luzerne County, has an intellectual disability and various psychiatric diagnoses. Her disabilities substantially limit her major life activities, including thinking, learning, caring for herself, and interacting with others.

213. At an early age, she was removed from her family home by the county Office of Children, Youth, and Families due to abuse. Growing up, she lived with a variety of foster care families and then was placed at a residential treatment facility.

214. Just before she turned 19 years old, D.L. was enrolled in the Consolidated Wavier effective October 8, 2013.

215. After spending some time in a residential habilitation program funded by the Consolidated Waiver, D.L. began exhibiting aggressive behaviors and returned to her mother's home on March 20, 2014.

216. D.L. was admitted to First Hospital's psychiatric unit on March 25, 2014.

217. Between March 25 and the end of June, 2014, D.L.'s supports coordinator attempted but was not able to locate a residential provider for D.L. D.L. remained at First Hospital with no place to go.

218. In July 2014, staff of First Hospital filed a petition to have D.L. committed to a state-operated ICF/IID. In the petition, noting that efforts to secure D.L. a residential placement in the community had been unsuccessful, the certifying doctor wrote that he was recommending placement in a state-operated ICF/IID "in the interim between this hospital and a permanent placement."

219. D.L. was committed in a July 8, 2014 hearing and was transferred to Polk Center, one of the state-operated ICFs/IID. She was 20 years old. D.L. remains at Polk Center and regularly expresses her desire to be discharged and returned to the community.

j. Karen Blakely

220. Ms. Blakely is a resident of Philadelphia who has diagnoses of an intellectual disability and bipolar disorder. Her disabilities substantially limit her major life activities, including thinking, learning, caring for herself, and interacting with others

221. In 2005, Ms. Blakely was placed in a one-person residential habilitation program funded through the Consolidated Waiver. She lived there until 2009, when her mother removed her after she sustained second-degree burns when staff threw hot water on her in response to a behavioral incident. At that time, Ms. Blakely's mother took her home.

222. After she returned to her mother's home, she received only limited services through the Consolidated Waiver.

223. In February 2010, Ms. Blakely's behavioral issues worsened and she became assaultive toward her mother.

224. In June 2010, Ms. Blakely was admitted to a private psychiatric hospital in Philadelphia.

225. At the hospital, the doctors took Ms. Blakely off of her medications, resulting in a marked improvement in her functional abilities.

226. Ms. Blakely's AE identified a provider willing to offer her residential habilitation services in the summer of 2010. The provider and

ODP negotiated for more than a year, but were unable to negotiate a rate acceptable to the provider to serve Ms. Blakely. During those negotiations, Ms. Blakely remained institutionalized in the psychiatric hospital.

227. By the spring of 2011, the private psychiatric hospital where Ms. Blakely was confined indicated that it would initiate proceedings to commit her to a state-operated ICF/IID given the lack of progress in developing a community residential habilitation program for her.

228. In June 2011, Ms. Blakely joined a lawsuit, *Mumford v. Dep't of Public Welfare*, Civil Action No. 11-3312 (E.D. Pa.), filed by DRN to challenge her unnecessary institutionalization and DHS's failure to offer her services in the community, the most integrated setting appropriate to her needs.

229. After the lawsuit was filed, DRN filed a motion for temporary restraining order and preliminary injunction and took discovery.

230. DHS identified a residential habilitation provider to serve Ms. Blakely, and the parties entered into a settlement agreement in September 2011 to resolve the litigation.

231. Ms. Blakely was finally discharged from the psychiatric hospital to a residential habilitation provider in early 2012 – approximately 18 months after she was appropriate for discharge.

D. Systemic Obstacles to Timely Accessing and Maintaining Residential Habilitation Services through the Consolidated Waiver.

232. Consolidated Waiver participants with complex and challenging needs – specifically those with mental illness and those with significant medical needs – often encounter particular difficulties in accessing and/or maintaining residential habilitation and other services necessary to avoid institutionalization and remain in their communities.

233. Systemic obstacles impede providers' agreement to serve these participants in residential habilitation programs and impede those participants' long-term success in such programs even when providers do agree to serve them. These systemic obstacles include, but are not limited to, those listed below.

234. ODP acknowledged the deficits in its community-service system for individuals with dual diagnoses of intellectual disability and mental illness and that these deficiencies lead to unnecessary admissions to state institutions for people with intellectual disabilities, hospitals, and psychiatric hospitals. Admissions to State Operated Intermediate Care Facilities for Persons with Intellectual Disabilities, ODP Informational Memo 045-12 (June 8, 2012).

235. In June 2012, ODP outlined various steps it would take to better address the needs of individuals with dual diagnoses of intellectual disability and mental illness with the goal of having zero admissions to state institutions for individuals with intellectual disabilities for a 12-month period beginning in July 2012. Admissions to State Operated Intermediate Care Facilities for Persons with Intellectual Disabilities, ODP Informational Memo 045-12 (June 8, 2012).

236. Instead, at least 30 individuals have been committed to those state institutions since July 1, 2012, one as recently as days before the filing of this Complaint. Many other Consolidated Waiver participants have been unnecessarily institutionalized in state hospitals, private psychiatric hospitals, nursing facilities, and other inappropriate settings since that time.

1. Inadequate Crisis Supports and Services

237. The Consolidated Waiver does not fund crisis services (such as mobile crisis and technical support for direct care staff) that can be used by participants in residential habilitation programs to help them if they experience significant crises that cannot be readily addressed by their staff.

238. Crisis services are available primarily through the mental health system, but most of those services do not have staff with expertise in

supporting individuals with dual diagnoses of intellectual disability and mental illness.

239. Although the Consolidated Waiver funds overnight respite care, it is not adequate to provide crisis relief.

a. On information and belief, there are insufficient overnight respite programs who are willing and have the expertise to provide effective crisis services to individuals with dual diagnoses of intellectual disability and mental illness so that they can stabilize and return to their residential habilitation programs.

b. In addition, the Consolidated Waiver generally caps overnight respite care at 30 days a year which is insufficient to provide relief for Consolidated Waiver participants whose residential habilitation providers have terminated them since it can take months to identify and develop new residential habilitation programs.

240. Consolidated Waiver participants with dual diagnoses of intellectual disability and mental illness who require emergency or short-term psychiatric hospital care are usually placed in hospitals that lack experience in serving individuals with intellectual disabilities. On information and belief, there are only two hospitals in Pennsylvania with

expertise in providing psychiatric treatment to individuals with intellectual disabilities and they often have waiting lists.

241. In March 2014, ODP's "Futures Planning" Action Team indicated that ODP should "integrate flexible models of service that can support people's changing needs in their home communities, including supporting people through a physical or behavioral crisis." The Action Plan included developing a "Crisis Assistance/Support/Stabilization Team" to assist providers in preventing crises and supporting individuals through crises and designing and developing support programs that can assist individuals in transitions and crises. On information and belief, nearly two years later, these plans have not been implemented.

2. <u>Inadequate and Uncertain Payment</u>

242. Prior to July 2009, residential habilitation providers negotiated with and were paid rates by County MH/ID Programs (using allocations from DHS).

243. In July 2009, DHS began paying residential habilitation providers directly for those services.

244. DHS pays two rates for each individual served in a residential habilitation program: (a) the "eligible rate," which is supposed to cover costs eligible for federal financial participation under Medicaid, and (b) the

"ineligible rate," for room and board costs that are not eligible for federal financial participation and are paid solely using state dollars.

245. DHS uses a "cost-based" rate system to annually determine the eligible rate for each residential habilitation program administered by each provider.

246. DHS begins the process to establish the eligible rates by reviewing cost reports that providers submit for each of their residential habilitation programs.

247. DHS reviews providers' submitted cost reports to identify residential habilitation programs that are "outliers."

248. If DHS determines that an existing residential habilitation program is not an outlier, DHS assigns an eligible rate based on the cost report. Because the cost report reflects costs that are at least one year old, the assigned rate may be insufficient to reimburse the provider for its actual costs.

249. If DHS determines that an existing residential habilitation program is an outlier, DHS will assess whether the residents' ISPs justify the increased costs. If DHS determines that the ISPs do not justify the increased costs, DHS reduces the eligible rate assigned to the program, resulting in rates that may not cover the provider's actual costs.

250. Since residential habilitation programs that serve Consolidated Waiver participants with challenging needs have higher costs and thus are more likely to be deemed "outliers," they are more at risk of rate reductions by DHS.

251. On information and belief, DHS has used the outlier assessment process to reduce rates for residential habilitation programs that serve Consolidated Waiver participants with complex or challenging needs.

252. On information and belief, DHS's reduction of rates for residential habilitation programs that serve Consolidated Waiver participants with complex or challenging needs using the outlier assessment process has resulted in rates that are not sufficient to cover providers' costs to serve those clients.

253. If the General Assembly approves, DHS may apply a cost of living adjustment (COLA) to increase eligible rates for residential habilitation. However, no COLAs have been authorized for residential habilitation since at least Fiscal Year 2012-13.

254. DHS may apply a "rate adjustment factor" to reduce both eligible and ineligible rates for residential habilitation services to assure that aggregate payments do not exceed the amount appropriated by the General Assembly. Although DHS has not used the rate adjustment factor

in the past several fiscal years, it has been used in previous years to reduce rates. On information and belief, the use of the rate adjustment factor resulted in providers' inability to recover the costs incurred to provide residential habilitation programs.

255. Often, Consolidated Waiver participants who have complex or challenging needs cannot be served in existing residential habilitation programs and need to have new programs created to meet their needs.

256. For new residential habilitation programs, DHS assigns an eligible rate that is either: (a) based on the average of the provider's cost-based rates if the provider operates other residential habilitation programs, or (b) based on the adjusted average of other providers' cost-based rates in the geographic area if the provider has never offered residential habilitation services.

257. The rates for new residential habilitation programs are not based on the actual projected costs for those programs given the Consolidated Waiver participants' unique needs, but on the needs of participants in other residential habilitation programs who may not have complex or challenging needs.

258. On information and belief, DHS has a "high cost" process that it may use to set rates for residential habilitation programs intended to serve

Consolidated Waiver participants with complex or challenging needs. DHS does not publicize that this process exists or how it works, but simply instructs providers to contact the ODP's Regional Fiscal Officer. Further, there are no timelines within which the request for a high cost rate must be resolved, which can lead to delays in developing services for participants.

259. Aside from the inadequacy of eligible rates for residential habilitation services to incentivize providers to serve Consolidated Waiver participants with challenging needs, the ineligible rates paid by DHS for room and board are also inadequate. The current ineligible rates are about $25,000 per program annually. Even with the additional contribution that the participants pay from their benefits and the availability of food stamps and other supports, the ineligible rates may not be adequate to cover all of the ineligible costs such as utilities, water, sewage, maintenance, and repairs. The ineligible rates are also subject to application of the downward rate adjustment factor.

260. Providers are hesitant to offer residential habilitation services to Consolidated Waiver participants with complex or challenging needs not only because of the inadequate amount of the rates, but also due to the uncertainty built into the rate-setting system. Providers have had experiences where they agree to serve a challenging participant at a rate

that is sufficient, but within a year or two DHS reduces the rate – whether through the outlier process or application of the rate adjustment factor or otherwise – to a point where it is insufficient to meet the costs of the program, particularly when combined with a lack of COLAs. Providers whose costs exceed their compensation are then unwilling to continue to serve those participants or to accept new participants with challenging needs – regardless of the rate offered – due simply to fear that the rates will be reduced.

261. Another cost-related factor adversely affecting the willingness of providers to offer residential habilitation services to Consolidated Waiver participants with challenging needs is the lack of adequate funding for start-up costs to develop new residential habilitation programs, which are often required for such participants who cannot readily fit into vacancies in existing programs.

262. DHS caps start-up costs for new residential habilitation programs at $5,000 per resident.

263. Start-up costs include such items as staff salaries and training, but exclude reimbursement for the acquisition or construction of long-lived assets, such as housing.

264. Even allowable start-up costs for a new residential habilitation program to serve a Consolidated Waiver participant with complex or challenging needs are likely to significantly exceed the cap of $5,000 per resident.

265. One provider estimated start-up costs for a three-person home for individuals with challenging behavioral health needs at $84,000.

266. DHS's expectation that providers absorb the excluded start-up costs and those in excess of $5,000 per person further limits providers' willingness to create new residential habilitation programs for Consolidated Waiver participants with challenging needs.

3. Staffing Challenges

267. Consolidated Waiver participants with behavioral health or medical needs can be difficult to serve, resulting in support staff frustration and turnover.

268. The rate system, and especially the lack of COLAs, results in low wages and high staff turnover, making it even harder to recruit and retain staff with the skill level needed to serve Consolidated Waiver participants with complex or challenging needs.

269. The Consolidated Waiver permits enhanced staffing for participants with challenging behavioral health or complex medical needs, including nursing or 1:1 or 2:1 staffing.

270. ODP must authorize enhanced staffing based on the supports coordinator's documentation of the participant's need for it, how it will be used to address the participant's need, and a timeframe to reduce the enhanced staffing (before it even begins).

271. On information and belief, the process to secure ODP approval for enhanced staffing is time-consuming, making it difficult for providers to promptly provide enhanced staffing when necessary to meet the needs of a challenging resident in crisis or forcing the providers to pay for the enhanced staff and risk non-reimbursement by DHS.

272. The inability to timely secure ODP approval for enhanced staffing further deters providers from serving Consolidated Waiver participants with complex or challenging needs who may need enhanced staffing in the future.

4. Lack of Consequences for Termination

273. Consolidated Waiver participants with complex or challenging needs are more likely than other participants to be subject to termination by residential habilitation providers.

274. When a residential habilitation provider terminates services, it can mean the loss of the participant's home and the need to find a new provider and a new home.

275. When a provider is no longer willing or able to serve a Consolidated Waiver participant, it must provide 30-days' written termination notice to the participant, his or her supports coordinator, the AE, and any legal representative of the participant. 55 Pa. Code § 51.31(e).

276. The 30-days' notice requirement is a "minimum requirement." ODP Information Memo. 069-13 at 16 (Aug. 29, 2013). State law requires a provider who terminates a Consolidated Waiver participant's services to continue to serve the participant until he or she can be transitioned to a new provider unless the provider gives written notice to DHS that it cannot do so due to "emergency circumstances." 55 Pa. Code §§ 51.31(e)-(f).

277. Although state law requires a provider to continue to serve the Consolidated Waiver participant until he or she can be transitioned to a new residential habilitation program to assure continuity of care, 55 Pa. Code § 51.31, providers frequently do not comply with that obligation.

278. On information and belief, DHS allows providers to terminate residential habilitation services before new providers are identified for

Consolidated Waiver participants and imposes no consequences for providers who refuse to continue to provide services to participants before they can be transitioned to new providers.

5. Inadequate System to Identify Willing Providers

279. Currently, DHS relies primarily on the Consolidated Waiver participants' supports coordinators to locate residential habilitation providers for those participants who newly request those services and for those who have been terminated by their existing providers.

280. On information and belief, supports coordinators are permitted to review vacancy lists for local programs to see if participants can fit into existing residential habilitation programs.

281. On information and belief, if the supports coordinator cannot identify a vacancy in an existing, local residential habilitation program appropriate for the participant, the supports coordinator will be permitted to review the statewide vacancy list to determine if the participant can fit into an existing residential habilitation program elsewhere in Pennsylvania.

282. On information and belief, when supports coordinators cannot identify vacancies that are available and appropriate to serve a Consolidated Waiver participant, the process often comes to a halt. On information and belief, there is no means by which the supports coordinators can

begin the process to identify a provider who is willing to develop a new residential habilitation program to serve the participant.

283. The lack of an established system to assist supports coordinators to promptly identify providers able and willing to serve Consolidated Waiver participants with complex or challenging needs, either through vacancies or the creation of new programs, further delays participants' ability to timely access such services.

284. DHS has no timelines for when a Consolidated Waiver participant who requests residential habilitation services will be provided those services.

285. DHS has no system to track efforts to identify willing and able providers for Consolidated Waiver participants who seek residential habilitation services or to intervene if the process does not promptly identify willing and able providers.

6. Lack of Capacity

286. DHS does not have sufficient capacity in its Consolidated Waiver program to timely serve participants with complex or challenging needs who seek such services initially or need to transfer from programs from which they have been terminated.

287. DHS has not assured that it has sufficient providers who have expertise and a track record of success in serving individuals with complex or challenging needs.

288. On information and belief, many providers cannot offer effective residential habilitation services to Consolidated Waiver participants with complex or challenging needs because they do not have funding available to pay professionals with expertise who can serve as resources to serve those participants.

V. Claims

A. Count I: Prompt Access to Residential Habilitation Services Under Title XIX

289. Paragraphs 1 through 288 are incorporated by reference as if fully set forth herein. This Count is brought against Defendant Dallas for actions and omissions in his official capacity under color of state law.

290. Under Title XIX, states that participate in the Medical Assistance program, including Pennsylvania, must make Medical Assistance benefits available to eligible persons. 42 U.S.C. § 1396a(a)(10)(A).

291. Title XIX provides that HCBS Waiver services approved by CMS constitute "Medical Assistance" under the state plan. 42 U.S.C. § 1396n(c)(1).

292. Since CMS has approved the Consolidated Waiver, the services provided under that HCBS Waiver are "Medical Assistance" services that must be made available to eligible individuals.

293. Once in an HCBS Waiver, participants must be provided with access to all services available under the Waiver that they need. *See Olmstead Update No. 4* (Jan. 10, 2001).

294. Since residential habilitation is a service funded by the Consolidated Waiver, participants in that Waiver have an entitlement under Title XIX to receive that service if it is appropriate for them.

295. Title XIX further mandates that Medical Assistance shall be furnished with "reasonable promptness to all eligible individuals." 42 U.S.C. § 1396a(a)(8). Defendant thus must furnish Medical Assistance, including residential habilitation and other services under the Consolidated Waiver, promptly and without any delay caused by the agency's administrative procedures. 42 C.F.R. § 435.930(a).

296. Plaintiffs Spurri and Miller are Consolidated Waiver participants who want, need, and are eligible for residential habilitation services.

297. Plaintiffs Spurri's and Miller's parents have tried repeatedly and over periods in excess of one year to access residential habilitation services for them. Those efforts have proved fruitless.

298. In addition to Plaintiffs Spurri and Miller, Plaintiff DRN is aware of and has intervened on behalf of other Consolidated Waiver participants who have complex medical needs or challenging behavioral health needs and who have either been unable to access residential habilitation and other services necessary to avoid institutionalization or have been unable to promptly access such services.

299. DHS has no timelines governing when residential habilitation services must be provided to Consolidated Waiver participants who seek such services.

300. DHS's policies and practices impede the timely availability of residential habilitation services for Consolidated Waiver participants with challenging needs.

301. Defendant Dallas's actions and omission under color of state law that have resulted in the failure to assure that Plaintiffs Spurri and Miller and other Consolidated Waiver participants have access and/or timely access to residential habilitation services violate 42 U.S.C. §§ 1983, 1396a(a)(8), and 1396a(a)(10)(A).

B. Count II – Comparability Under Title XIX

302. Paragraphs 1 through 301 are incorporated by reference as if fully set forth herein. This Count is brought against Defendant Dallas for actions and omissions in his official capacity under color of state law.

303. Title XIX requires DHS to assure that the Medical Assistance benefits available to a "categorically needy" beneficiary are not "less in amount, duration, or scope than the medical assistance made available to any other" categorically needy beneficiary or to a medically needy beneficiary. 42 U.S.C. § 1396a(a)(10)(B).

304. DHS provides residential habilitation services to many other Medical Assistance participants who participate in the Consolidated Waiver.

305. Plaintiffs Miller and Spurri are categorically needy Medical Assistance participants who are eligible for residential habilitation services through the Consolidated Waiver, but have been unable to receive those services.

306. Other Consolidated Waiver participants with complex or challenging needs eligible for residential habilitation services have been unable to receive those services.

307. Defendant Dallas's actions and omissions that preclude Plaintiffs and other Consolidated Waiver participants with complex or challenging needs from accessing appropriate residential habilitation services comparable to the access afforded to other Medical Assistance beneficiaries violate 42 U.S.C. §§ 1983 and 1396a(a)(10)(B).

C. Count III – Violations of the ADA and RA

308. Paragraphs 1 through 307 are incorporated by reference as if fully set forth herein.

309. This Count is brought solely against Defendant DHS with respect to Section 504 of the Rehabilitation Act (RA) and against Defendant Dallas for actions and omissions in his official capacity under color of state law with respect to Title II of the Americans with Disabilities Act (ADA).

310. Plaintiffs and other Consolidated Waiver participants have intellectual disabilities, impairments that substantially limit one or more of their major life activities including but not limited to caring for themselves, learning, concentrating, thinking, and interacting with others. As such, Plaintiffs and other Consolidated Waiver participants are persons with disabilities protected by the ADA, 42 U.S.C. §§ 12102(1)(A), 12102(2)(A), and the RA, 29 U.S.C. § 705(20)(B).

311. Plaintiffs Spurri and Miller and other Consolidated Waiver participants are eligible for and participate in the Medicaid Consolidated Waiver, and as such are qualified persons with disabilities under the ADA and RA.

312. DHS, administered by Defendant Dallas, is a public entity subject to the requirements of Title II of the ADA. 42 U.S.C. § 12131(1)(B).

313. DHS is a recipient of federal financial assistance and, as such, is subject to the requirements of Section 504 of the RA. 29 U.S.C. § 794(b).

314. Plaintiffs Spurri and Miller and other Consolidated Waiver participants are appropriate for and want to live in the community.

315. The community is the most integrated setting appropriate to meet the needs of Plaintiffs Spurri and Miller and other Consolidated Waiver participants.

316. Residential habilitation services funded by the Consolidated Waiver allow participants who need those services to live in integrated community settings.

317. Plaintiffs Spurri and Miller are at serious risk of institutionalization in state-operated or private ICFs/IID if they cannot secure prompt

access to residential habilitation services since their families can no longer maintain them in their family homes.

318. Due to the lack of timely access to residential habilitation services, certain Consolidated Waiver participants have been institutionalized or at serious risk of institutionalization in state-operated ICFs/IID, state-operated psychiatric hospitals, private psychiatric or medical hospitals, or nursing facilities.

319. Defendants violate the integration mandate of Title II of the ADA, 42 U.S.C. § 12132 and 28 C.F.R. § 35.130(d), and Section 504 of the RA, 29 U.S.C. § 794 and 28 C.F.R. § 41.51(d), by failing to assure Plaintiffs' and other Consolidated Waiver participants' timely access to residential habilitation and other services necessary to avoid institutionalization and allow them to live in the community.

320. Defendants violate Title II of the ADA, 42 U.S.C. § 12132 and 28 C.F.R. § 35.130(b)(7), and Section 504 of the RA, 29 U.S.C. § 794, by failing to make reasonable modifications to allow Plaintiffs and other Consolidated Waiver participants timely access to residential habilitation services. Such modifications include, but are not limited to: (a) funding a range of specialized crisis services for individuals with dual diagnoses; (b) implementing a rate system to incentivize providers to provide residential

habilitation services for Consolidated Waiver participants with challenging or complex needs; (c) assuring that providers' reasonable start-up costs to develop new residential habilitation programs are reimbursed; (d) implementing and monitoring timelines to assure that Consolidated Waiver participants have timely access to residential habilitation services and a system to timely identify residential habilitation providers and develop residential habilitation programs for participants with complex or challenging needs; (e) imposing consequences when providers terminate residential habilitation services before the participant can be transferred to a new residential habilitation program; and (f) expanding the number of providers with expertise in providing residential habilitation services to participants with complex or challenging needs.

321. Defendants violate Title II of the ADA, 42 U.S.C. § 12132 and 28 C.F.R. § 35.130(b)(3), and Section 504 of the RA, 29 U.S.C. § 794 and 28 C.F.R. § 41.51(b)(3), by using methods of administration, including those described in Section IV.D of this Complaint, that: (a) subject Plaintiffs and other Consolidated Waiver participants to discrimination through unnecessary institutionalization or serious risk of unnecessary institutionalization; (b) subject Plaintiffs and other Consolidated Waiver participants to discrimination by excluding them from residential habilitation

services based on their diagnoses of mental illness, physical disabilities, and/or the severity of their disabilities; and (c) have the effect of defeating or substantially impairing accomplishment of the objectives of the Consolidated Waiver with respect to individuals with diagnoses of mental illness and/or with more severe disabilities.

322. Plaintiffs and other Consolidated Waiver participants who have severe mental or physical health problems are effectively denied the opportunity to participate in and benefit from residential habilitation services in violation of Title II of the ADA, 42 U.S.C. § 12132 and 28 C.F.R. §§ 35.130(a)-(b)(1)(i), and Section 504 of the RA, 29 U.S.C. § 794 and 28 C.F.R. § 41.51(a)-(b)(1)(i).

VI. Relief

323. Plaintiffs respectfully request that the Court:

a. retain jurisdiction over this action;

b. declare that Defendants' actions and inactions violate 42 U.S.C. § 1983, Title XIX of the Social Security Act, the Americans with Disabilities Act, and the Rehabilitation Act;

c. issue appropriate injunctive relief to enjoin Defendants from continuing to violate 42 U.S.C. § 1983, Title XIX of the Social Security

Act, the Americans with Disabilities Act, and the Rehabilitation Act and to take appropriate steps to remedy their violations; and

d. issue such other relief as may be just, equitable, and appropriate, including an award of reasonable attorneys' fees, litigation expenses, and costs pursuant to 42 U.S.C. §§ 1988, 12205 and 29 U.S.C. § 794a(b).

Dated: January 19, 2016

By: /s/ Kelly Darr

Kelly Darr (PA ID 80909)
Robin Resnick (PA ID 46980)
Disability Rights Network of PA
1315 Walnut Street, Suite 500
Philadelphia, PA 19107-4705
(215) 238-8070
(215) 772-3126 (fax)
kdarr@drnpa.org

By: /s/ Carol Horowitz

Carol Horowitz (PA ID 81660)
Shari Mamas (PA ID 78321)
Disability Rights Network of PA
429 Fourth Avenue, Suite 701
Pittsburgh, PA 15219-1505
(412) 391-5225
(412) 467-8940 (fax)
chorowitz@drnpa.org

Counsel for Plaintiffs